

Welsh government consultation on “children missing education” databases and regulations for LAs and Local Health Boards

1. Objections to the proposals

1.1 Driving families away from public services and increasing risk to children

The Welsh government’s **children’s rights consultation impact assessment** (CRIA s3)¹ to accompany the consultation notes the risk that once it is known that health data would be used for non-health purposes, some families may choose not to present children to healthcare services. The proposal makes no mitigations for this harm caused by the policy as outlined, to individuals or public health.

“One identified potential negative effect of the proposals is the potential for families to fail to register with a GP if they felt strongly that they didn’t want their details shared with local authorities”.

This alone should end the plans, making them too high risk for the very children suggested could be identified in this way. Not only failing in its intended aim but causing more harm.

The outcome of these proposals will be likely to make any vulnerable children *less* visible and *less* able to access healthcare, external care input and educationally enriching experiences than today. This known effect was also foreseen by the Welsh Government. The then Education Minister Kirsty Williams, on introducing these proposals in 2018, said of putting a mandate onto parents instead of local authorities:

“I suspect this element of compulsion could have the unintended consequence—the very real unintended consequence—of driving those parents further away from engagement with statutory services”.²

There is no mitigation of the risk (of children being removed from the health service) offered.

1.2 Data confidentiality and damage to public trust

Non-consensual data-sharing from health care sources is unethical and damaging, affecting the trust-based clinician-patient relationship and creating barriers to accessing healthcare.

As explained online by HE Byte³ in its article, **Why hasn’t the Welsh Government Listened to the General Medical Council?** The GMC objected strongly in 2020 to similar proposals⁴, stating that non-clinical health records should be treated with the same confidentiality as clinical records. They also predicted harm to families and public health:

¹Children’s Rights Impact Assessment (CRIA) Archived February 2024
<https://web.archive.org/web/20240225120655/https://www.gov.wales/childrens-rights-impact-assessment-draft-children-act-2004-children-missing-education-database>

² Plenary 30/01/2018 Welsh Parliament (para 395)
https://record.assembly.wales/Plenary/4901?fbclid=IwAR0_Kzg5y2WBAVboIhMdBwvRjFWpXSy-5AwgGVP03Kkhh8xp8MXJnZvhQU_aem_AYj-K0yJSpWhCsTt_-5mW7lyRC-pqXELRBH1mexyOtMJ693Ctrn6Cf86mvL6u5XYxhsKhVf2HyvU0tLOxNJJ69se#A10000068

³ HE Byte (April 2024) <https://he-byte.uk/wales/why-hasnt-the-welsh-government-listened-to-the-general-medical-council/>

⁴ GMC 2020 consultation response: The Draft Children Act 2004 Database (Wales) Regulations 2020 and the Draft Education (Information about Children in Independent Schools) Wales) Regulations 2020
Consultation <https://www.gmc-uk.org/-/media/documents/gmc-response-to-welsh-government-consultation---local-health-board-disclosures-t-o-local-aut-84392705.pdf>

“Requiring doctors to share information about children and young people and their parents could cause some to disengage with health services, affecting not only their health but also potentially the health of their local communities.”

A 2024 report, *Confidentiality and Respect: Impact of Attitudes and Conduct of Healthcare Professionals towards Home Educating Families*, also demonstrated the harmful impact of non-consensual data sharing from healthcare services for home educators.⁵

Furthermore, there is a chilling effect on candour. Research⁶ has found that people who are told that their answers in interviews would not be kept confidential, provided less intimate and frank information.

There are clear precedents to demonstrate that non-consensual data-sharing is unsafe and counterproductive, making clinicians less able to exercise their routine safeguarding role:

- ContactPoint⁷ scrapped in 2010;⁸
- NHS data sources on asylum seekers in 2018 as part of screening for illegal activity;
- The Royal College of Obstetricians and Gynaecologists (RCOG) 2024 guidance on the confidentiality of women and involvement of the police and external agencies following abortion, pregnancy loss and unexpected delivery.⁹

About ContactPoint, Children's Minister Tim Loughton in 2010 said, ***“We need a better child protection system in this country, but at the end of the day it's not a computer system that will save vulnerable children. It's the performance of the professionals at the sharp end, who need to be properly trained and resourced.”***¹⁰

This plan will inevitably increase the risk of data breaches, where data is stored on council lists and databases rather than within tightly governed NHS data models.

1.3 Legislative overreach

In the Welsh Government's attempts to take *“a real opportunity to test the fullest extent of existing legislation”*, boundaries are overstepped rather than stretched in the depictions of legislation and legal duties of authorities.

For example, s175 of Education Act 2002 is used to depict a duty of LAs of safeguarding and well-being as if it applies to every child in the country. However, s175 refers only to duties of local authorities in relation to institutions with governing bodies, where parents have chosen to delegate responsibilities to those bodies. Even in those situations, s175 does not grant authority for authorities to take over such responsibilities but rather have *“a view”* to these when exercising educational functions in relation to those institutions.

The meaning of the Education Act 1996 is also represented differently than the text of the legislation, changing the meaning of the term *“missing education”* from *“are not”* in the legislation to *“may not be”*. The lawful duties of authorities are therefore misrepresented and

⁵ McKee, R.Dr. (2024) Confidentiality and Respect: Impact of Attitudes and Conduct of Healthcare Professionals towards Home Educating Families

<https://selfmanagedlearning.org/wp-content/uploads/2024/04/Confidentiality-and-Respect-Report-March-2024.pdf>

⁶ Woods and McNamara, "Confidentiality: Its Effect on Interviewee Behavior," 11 *Prof. Psychology* 714, 719 (1980)

⁷Deloitte (2008) ContactPoint data security review final report

https://web.archive.org/web/20231221091932/https://assets.publishing.service.gov.uk/media/5a74881ce5274a7f99028f07/deloitte_20contactpoint_20dsr_20report.pdf

⁸ <https://researchbriefings.files.parliament.uk/documents/SN05171/SN05171.pdf>

⁹<https://www.rcog.org.uk/news/rcog-issues-guidance-for-healthcare-professionals-on-involving-the-police-following-abortion-and-pregnancy-loss/> (January 2024) RCOG

¹⁰ <https://www.bbc.co.uk/news/education-10887082>

misquoted (intentionally or otherwise) but may appear to seek to justify attempts to increase data-sharing powers, increasing the extent of data required, and breadth of persons from whom personal confidential data on others and themselves can be mandated.

The wide range of in-depth data required and the open-ended and potential for far greater range of data to be mandated by enactment of s29 (Children's Act 2004) make this a starting proposal with in-built intention for scope creep. This is a poor basis for trust.

According to the 2021 Census,¹¹ 16.5% of the population (513,800) in Wales were aged under 15 years (the interval 5-16 may be estimated to be within a similar range as 0-15). The proposals would mean first handing over data from confidential health records to councils on these ca. half million children in Wales, the overwhelming majority of whom (according to the consultation's own description) are known to Local Authorities and also in education. This creates "lists" and then from those, new "databases", not on the basis that they ARE at any risk of not being in receipt of education, but that they merely "*might be*" not in receipt of suitable education.

"Most children will be attending school or EOTAS provision or EHE and known to be in receipt of a suitable education. Only the names of children who are not known to the LA, or known to the LA but they have been unable to determine whether the education being provided is suitable, will be included on the database."¹²

However this omits the fact that every child's record will first be processed by default.

2. Data Governance

2.1 Lack of clarity over the data sources

The Welsh government proposal will mandate Local Health Boards (LHBs) and general medical services contractors to be used as data lakes as the initial sources of children's records for each local council's separate data matching exercise. The example given is of GPs only ("*for example, a GP surgery*") however the GMS contract¹³ reach is far wider extending to contraceptive services, childhood vaccines and immunisations services, child health surveillance services, dentists, midwifery and nursing, mental health services, opticians, podiatrists, pharmacist or independent prescribers.

The full extent of these services is unclear. It is not explicitly defined in either the consultation or question 5(iii) "Local health boards and general medical contractors".

There is no *necessity* to extract the personal data of the overwhelming majority of children for this purpose from their health records at all. It is therefore also clearly disproportionate in the case of nearly half a million individual data subjects. **This fails the two basic tests of UK data protection law, the underpinning GDPR as well as the Convention 108.**

"Necessary in a democratic society" furthermore is a test found in human rights law, namely articles 8–11 of the European Convention on Human Rights (ECHR), which provide that the

¹¹ ONS (2021) Census 2021 rounded population and household estimates for local authorities in Wales, by sex and five-year age group <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/populationandhouseholdestimateswales/census2021>

¹² Consultation section "How will the database operate"

<https://web.archive.org/web/20240222170551/https://www.gov.wales/children-missing-education-database.html>

¹³ https://assets.publishing.service.gov.uk/media/5a7ac3beed915d670dd7e6a4/Standard_General_Medical_Services_Model_Contract.pdf

state may impose restrictions of these rights only if such restrictions are "necessary in a democratic society" and proportional to the legitimate aims in each case.

There are no safeguards on how people will be informed their personal details are being extracted from health services, or clear limitations on where it may be sent or retained.

2.2 What personal data is involved from whom

These databases would require extensive amounts of data about children, families and unrelated adults connected to their education¹⁴ –

First, the initial "*lists*" (our italics indicating quoted wording as used in the consultation), will be created by extracting identifying data from health sources of every child known to services in Wales to include the names and contact details of the child, the child's address (or last known address), postcode, date of birth, the child's gender or if the child's gender has not been specified a statement to that effect.

Each council will then perform a cross-check of these lists containing every child in state but not private health registers against children in education, including state and private schools. "*Independent schools will share the same basic information with the LA about children on-roll at their school*".

This leaves each council with a subgroup of children labelled as, "*potentially missing education*" to be placed onto the relevant Local Authority's new "*database*".¹⁵

To these databases, councils will add the name and address of every person providing all or part of the education which is not explicitly described but could be inferred to include Sunday school teachers and religious groups, art, music, drama and sports activity providers, forest schools and youth groups, Scouts and Guiding groups, and fellow home educating parents when take part in shared learning times or home ed clubs and groups across Wales for example involved in Home Education. The sources or methods of obtaining these data are not specified in the consultation.

3. Additional matters for affected groups

3.1 For independent education settings

Private schools and education settings will be required to communicate with all of the authorities "*where the child was usually resident*" to share the personal details of every pupil on-roll.¹⁶ This will have implications for children not usually resident in Wales, from day pupils to boarders, as well as for their healthcare professionals.

Potential further complications may be foreseeable if children in their care for education are not registered with any of the Local Health Boards (LHBs) and general medical services contractors in scope. This, one must infer, would trigger a 'not matched' result in the process but if and how that would be acted on or what significance it may be assigned is unclear and must be made explicit.

¹⁴<https://www.gov.wales/sites/default/files/consultations/2024-01/children-act-2004-information-database-wales-regulations.pdf> (page 8)

¹⁵ This appears not to be as clear cut as meeting the terms set out as, "not known to be in receipt of suitable education otherwise than at a school (as set out in s436a of the Education Act)" but will conflate children who might be missing education with those who are in fact in education but not yet ruled out in the opinion of the LA. It also makes an assumption that child enrolled and on a school roll are in receipt of suitable education and would not include children with low attendance or out of school.

¹⁶ Consultation <https://www.gov.wales/children-missing-education-database-html>

3.2 For home educators

While the proposals are framed as creating databases only of Children Missing Education the outcome in reality is that Local Authorities are going to create registers of children and their families in Elective Home Education (EHE) in order to compare “*lists*” and create the “*databases*” of CME. Since this comparison is suggested as an annual duty it is inevitable that Local Authorities will be encouraged to retain these data that they did not previously.

If this is not the intention of the proposals then the obligation to delete such EHE data immediately after lists’ comparison, should be made explicit on the face of any regulation.

3.3 For marginalised communities

These proposals specifically single out, “*Gypsy, Roma and Traveller (GRT) learners whose families have made the decision to home educate*”, and the impact assessment explains at length what processes should be followed to record children as CME if they are working (but does not explain that these are existing processes and therefore this paragraph in the impact assessment does not in fact describe *impact* of the proposals). Under the Equality Act 2010, public bodies cannot discriminate against people on grounds of race, which in this case applies to the explicit singling out of families and children of the GRT community.

3.4 For child protection services

There is no impact assessment given on current service provision. There is a risk that additional administrative workload across already stretched local councils staffing will worsen current standards¹⁷ without bringing additional positive outcomes. In effect, adding more hay to the haystack with no more needles to be found.

There is a poor history of child safeguarding where the state takes over parental responsibility. From abuse in children’s homes¹⁸ to more recent child deaths¹⁹ local authority services have repeatedly failed to support *known* children-at-risk. Assessment must be made of how any resources invested in these proposals to identify *unknown* children would affect existing council staff workload, responsibilities and resources, before adding the unnecessary processing of additional children who “*might be*” at risk of missing education, but who are not at risk and for whom there are no welfare concerns.

4. Questions and challenges

- a. **Risk of creating harm to children:** What risk assessment has been done for children who *are* at a safeguarding risk but not in school and whose families may therefore decide to no longer present to healthcare services, because this would flag them to LAs. “*One identified potential negative effect of the proposals is the potential for families to fail to register with a GP if they felt strongly that they didn’t want their details shared with local authorities.*” Although the children’s rights consultation

¹⁷ Wales Online (2021) Wales among the worst in the world for children in state care
<https://www.walesonline.co.uk/news/wales-news/wales-among-worst-world-children-20461139>

¹⁸ The Guardian (2013) North Wales child abuse: more than 140 people say they were victims
<https://www.theguardian.com/uk/2013/apr/29/north-wales-child-abuse-victims>

¹⁹<https://www.theguardian.com/society/2022/oct/05/council-where-logan-mwangi-was-murdered-worryingly-dependent-on-a-gency-care>

impact assessment (CRIA s3)²⁰ notes this risk created by the proposal, the proposal makes no assessment of the level of this harm or mitigations.

- b. The Impact Assessment suggests a live pilot will aim to assess the level of harm. *“The potential risk is further mitigated as proposals will be piloted with a smaller number of local authorities, ahead of being implemented more widely.”* Any new harm must be assessed *before* being ‘piloted’ in a real-world scenario. Actual lives are not a test environment and identifying who does *not* present, is near impossible.
- c. What risk assessment has been done for children who are at a safeguarding risk from one parent and whose personal data must now be linked together with the details of both parents, since the proposals mandate, *“name, address, postcode, telephone number and email address of all parents of the child?”*
- d. **The rights and duties of parents**, legal guardians, or other individuals legally responsible for him or her, are enshrined in Art.3 of the UNCRC, adopted into law in Wales. This is omitted in the CRIA. Some children live with a relative who does not have parental responsibility. Others do not have parental responsibilities²¹ in law but in practice. Has this been defined and how will it be made consistent?
- e. What risk assessment has been done for children who are *not* a safeguarding risk and not in state education, and for whom the new process will create a chilling effect when presenting to healthcare services, if they believe any personal data about them may be shared with LAs, but without their sight of it, or their consent?
- f. There is a conflation of children at risk of missing education and children ‘at-risk’ i.e. in need of child protection in the consultation. It states that, *“If the LA does not know about a child it is responsible for, it is unable to undertake its duties in relation to safeguarding and welfare, and cannot be certain that the child is not at risk of harm.”* What duties these are and under what powers are not expressly stated. However, LAs are *not* responsible for every child, their parents are. The LA has a responsibility to identify children *not* in receipt of suitable education and not in school, but has no duty to identify those who are.
- g. **Discrimination:** Where is the risk assessment carried out for GRT community children of the targeted aims set out in the Impact Assessment, but described without assessment of the outcomes?
- h. **Data accuracy and implications for timely interventions:** The Consultation states, *“this will not be a central all-Wales database and it will not be live.”* Will the databases be accurate beyond the point of collection for 364 days a year?
- i. **Data governance:** There are fewer LHB areas (7) than Local Authorities (22). LHBs will need to identify and sort which children are “usually resident” in each LA to send them only those relevant children. Is there a mechanism to do this or will it require additional workload and/or result in unlawful, excessive data sharing?
- j. Collecting the name and address of every person providing all or part of the education will mean an enormous data collection exercise. There is no detail on how the data will be acquired from providers e.g. does this mean a mandated duty on

²⁰Children’s Rights Impact Assessment (CRIA) Archived February 2024
<https://web.archive.org/web/20240225120655/https://www.gov.wales/childrens-rights-impact-assessment-draft-children-act-2004-children-missing-education-database>

²¹ Parental rights and responsibilities <https://www.gov.uk/parental-rights-responsibilities/who-has-parental-responsibility>

home educators to provide the name and address of every person providing any contribution to their child's education?

- k. There is no information in the consultation if and how parents or any of the range of other adults whose data would be held on such databases would be informed what has been collected, retained, or passed around. There is no mention of if and how they will be able to see the content of what is held in relation to them on databases, including subjective opinions. There is no process for accuracy, there are no routes for correction or challenge of opinions. This process further disempowers children and families while creating more powers for Local Authorities.
- l. **Workload and costs:** This process would create new workload for healthcare professionals and the independent education sectors, as well as the Local Authorities to process the data of every child 5-16. The suggestion is that LAs should take on increased duties, "*in relation to safeguarding and welfare*". What will the impact be on existing service provision? There is no information available about data cleansing, formatting or interoperability requirements. What is the time and cost assessment ascribed to each body or sector? Who will pay for it?
- m. **Privacy impact:** The CRIA mentions, "*Article 16: Every child has the right to privacy. The law should protect the child's private, family and home life and that the proposals may challenge article 16, if the child didn't want their personal data shared with the local authority by the health board.*" The impact assessment does not offer any counterpoint or mitigation. Do the proposals simply plan to ignore it?
- n. **Incidental impact:** There is risk of incidental impact to families where both parents do not share the same approach to standard healthcare. One parent may choose to ensure a child attends regular check ups and vaccinations but the other does not. Would families be told that their scrutiny was triggered openly, covertly or not at all?
- o. **Horizon scanning:** With forward looking plans in health²² and education for national records services, what safeguards are in place for new risks from automated data extraction, the use of AI and data linkage that exceeds the expectations of those responding to the consultation with the expectations of today's infrastructure and that "each" LA would run its own databases?

The introduction of these proposals would require a commencement order and the enactment of s29 of the Children's Act 2004²³ according to the consultation, which would open the door to unprecedented and almost unlimited powers for whatever government minister were in post to mandate sharing of almost any data from whatever healthcare source or person they choose, without limitation or safeguards, and seemingly for whatever purpose the minister in post should decide beyond the currently stated use.²⁴

This would be an untrustworthy basis for the work that would require a strong societal contract with families and by its nature would undermine that basis for existing safeguarding work today. We recommend these proposals are rejected.

Defend Digital Me

April 25, 2024

²² Welsh Government (2023) Digital and data strategy for health and social care in Wales
<https://www.gov.wales/sites/default/files/pdf-versions/2024/1/2/1705403312/digital-and-data-strategy-health-and-social-care-wales.pdf>

²³ <https://www.legislation.gov.uk/ukpga/2004/31/section/29>

²⁴ See <https://www.legislation.gov.uk/ukpga/2004/31/section/29> (4f-h)